

A CROSS-INSURANCE COMPARISON OF NORTH CAROLINA CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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EXECUTIVE SUMMARY

Children with special health care needs (CSHCN) by definition have on-going health problems that frequently require health care services beyond periodic visits for health maintenance or acute health problems. For any new insurance program, the extent to which services used by CSHCN are covered benefits is an important consideration. The State Children's Health Insurance Program (SCHIP), a federal-state partnership, was authorized in 1997 to provide health insurance for the nation's poor children who reside in families with incomes that exceed Medicaid eligibility guidelines. In the fall of 1998, North Carolina implemented its SCHIP, North Carolina Health Choice for Children (NCHC or NC Health Choice) as a stand-alone, fee-for-service health insurance program. The study described here is one method the Women's and Children's Health Section of the North Carolina Division of Public Health is using to assess the ability of NC Health Choice to meet the needs of CSHCN.

In funding this study, the Division supported the inclusion of a sample of Medicaid children and a sample of children insured by the State Employees' Health Plan (SEHP). This allowed examination of the difference in experience among two groups of publicly insured children and children covered by an employment-based insurance program. A written survey was mailed to parents of children with special health care needs, as identified through ICD-9 codes on insurance claims. Fifteen hundred children were sampled from each of the three insurance plans. Within each insurance group, the sample was stratified on five diagnosis categories: asthma, other chronic diseases, developmental delay, attention deficit disorder or attention deficit hyperactivity disorder (ADD/ADHD), and mental health. The survey response rate for all insurance groups combined was 61.6%.

Through analysis of survey responses, this study examines the health care and ancillary services that NC parents report that their children require, across the three insurance plans and different diagnosis categories. It also examines the extent to which reported health care needs are being met, and the barriers that limit access to needed services.

Differences across insurance plans are consistent throughout the survey results and support a gradient of need and access to care that ranges from more need and less access for Medicaid children to less need and more access for SEHP children, with NCHC children falling in the middle. Although reported access to medical care, both general and specialty care, was relatively good for children in all three insurance programs, and unmet need for both general medical care and specialty care was relatively low overall, 10% of Medicaid parents reported unmet need for both types of care, double that of children in the other two insurance groups. Similarly, children on Medicaid were significantly more likely to have problems accessing ADD/ADHD or mental health/substance abuse services, with rates of unmet need twice as high as those for NCHC children for both types of services and three times that of SEHP children for ADD/ADHD services.

The encouraging news is that there do not appear to be major areas of unmet need for medical care. However, even though the percent of parents of children on Medicaid or NCHC who reported unmet need was relatively small, if these percentages are applied to large numbers of enrollees in the programs the absolute number of children with unmet need is large.

While most children have access to providers for care, children on Medicaid in particular, and to a lesser extent those on NCHC, were reported to be less likely to receive medical care in the private sector. This finding is problematic to the extent that some public providers do not offer comprehensive services. Consistent with differences in site of medical care, Medicaid children were most likely to receive special services at school or day care for their health or developmental condition, followed by NCHC children and children on SEHP. Also, children on Medicaid were more likely to receive ADD/ADHD and mental health services in the public sector than were children in either of the other insurance groups. The greater use of public providers by Medicaid children compared to NCHC children suggests that, should NCHC reimbursements levels decrease to Medicaid levels, there would be a movement of NCHC children away from the private sector, and the need to maintain a strong public safety net would increase.

Children in the Medicaid group used the emergency room (ER) more frequently than children in the other two insurance groups, with use being the lowest among children enrolled in SEHP. Parents of 34% of Medicaid children reported that they had taken their child to the ER at least once in the previous six months, compared to 25% of NCHC children and 15% of those covered by SEHP. Only two-thirds of ER visits were made because the parent believed their child's condition to be an emergency or they had been advised by a health care professional to seek care in the ER. One-third of parents sought ER care for other, presumably non-emergent problems. The percentage of parents who reported using the ER for non-emergent problems did not differ across insurance plans. Parental reports of the reasons for use of the ER indicate the need for more extensive primary care coverage, parental education, and family-friendly office policies.

Parents of children covered by SEHP reported better access to dental care than did parents of children on Medicaid and NCHC despite the fact that SEHP does not cover dental care and many children in SEHP probably do not have dental insurance. Medicaid children faced the greatest barriers with 23% of parents reporting that their children had unmet dental care need, compared to 18% of NCHC parents and 7% of SEHP parents. The findings of poor access to dental care, especially for Medicaid enrollees, are consistent with other studies of access to dental care for low-income children in North Carolina. Although the increased access seen for NCHC children compared to Medicaid children suggests that raising provider reimbursement might improve access for children on Medicaid, the access levels of NCHC children are still not adequate. Also, anecdotal reports suggest that there are a limited number of "slots" for dental care for low-income children either because dentists will not see any publicly insured children or limit the number of these patients they will accept. It is not clear how much dentists limit the number of publicly insured patients they will see because of reimbursement rates or for other reasons. To the extent that these limits are based on multiple factors, an increase in reimbursement rates alone will not ensure access. Other methods need to be found that will encourage dentists to serve low-income children and support families to enable them to keep appointments.

There were few reported barriers to receipt of prescription medication for any group of children. There were, however, significant differences in parents' ability to get needed medical equipment and supplies, with parents of children in NCHC reporting the most difficulty. While the majority of CSHCN do not appear to need medical equipment and supplies, for those who do, the inability of many NCHC children to obtain these items is worrisome. The program has

already addressed some of the barriers reported by parents. With the increase from \$250 to \$1,000 in the allowable cost for purchasing equipment without prior approval, some equipment reported by respondents as not available would now be. There were also reports of barriers imposed by some vendors who required that parents pay out-of-pocket for some supplies. This access problem could be addressed by changing the relationship between vendors and the insurance plan, possibly requiring that vendors not charge the parent and ensuring that reimbursement to vendors is timely. Finally, some parents commented on the limited number of supplies such as test strips that they could get for their child each month. These comments are puzzling since there are no such limits under either Medicaid or NCHC. It is possible that the monthly limit comes from the number of supplies indicated on the prescription written by the physician. If true, this is not a problem that can be addressed by changes to the insurance, but rather requires parental education regarding the necessity of contacting their physician for a new, larger prescription.

For all of the specialized therapies queried (respiratory, speech and physical/occupational therapy), parents of Medicaid children were significantly more likely to report that their child needed these services. Although the need was greatest among Medicaid children, SEHP children had more difficulty accessing therapy services, particularly speech therapy. Very few parents reported the need for either home health or respite care, but among parents with such need, unmet need was high.

In general, it appears that poverty creates access problems independent of insurance coverage, evidenced by reports of transportation barriers and barriers due to inconvenient office hours which reflect in part the often difficult and inflexible work schedules of the poor. Although Medicaid children are technically eligible for transportation services, it appears that not all families' needs are being met, possibly due to the differing methods of covering transportation needs in each county and the level of responsiveness to acute transportation needs.

In summary, the North Carolina Health Choice program appears to provide better access to services for children with special health care needs than does the Medicaid program, and NCHC parents often report access that is comparable to that of SEHP. However, it is not possible to separate out the relative effects on access to care that come from the general willingness of providers to serve low-income children, and the influence of provider reimbursement rates that affect provider willingness. Confounding the interpretation of these results is the socioeconomic gradient across the three insurance groups and the extent to which socioeconomic advantage contributes to good health in multiple facets of daily life. In addition, economically stressed parents may report less unmet need because of lowered expectations of the health care system and health insurance system, a factor that we were unable to measure in this study. Regardless, parents report that health insurance is an essential component in their efforts to keep their children healthy.

INTRODUCTION

Children with special health care needs (CSHCN) by definition have on-going health problems that frequently require health care services beyond periodic visits for health maintenance or acute health problems. Parents of CSHCN may seek care for their child from multiple providers including primary care pediatric providers, specialty care providers, and nonphysician providers of services such as speech, occupational or physical therapy. Need for prescription medication or durable medical equipment may be ongoing. Obtaining care for CSHCN is not only time-consuming but also often expensive.

Health insurance is an obvious concern for parents of CSHCN. Parents are likely dependent on insurance for payment of costly and cumulative health care bills and may be limited in their ability to change employers for fear of losing health care coverage. For any new insurance program, the extent to which services used by CSHCN are covered benefits is an important consideration.

The State Children's Health Insurance Program (SCHIP), a federal-state partnership, was authorized in 1997 to provide health insurance for the nation's poor children who reside in families with incomes that exceed Medicaid eligibility guidelines. In the fall of 1998, with funds available through the SCHIP initiative, North Carolina implemented North Carolina Health Choice for Children (NCHC or NC Health Choice) as a stand-alone, fee-for-service health insurance program. This comprehensive health insurance program provides coverage for preventive and acute health care, dental care, prescription medication, eyeglasses, and other ancillary health care services for children who do not qualify for Medicaid but have family incomes at or below 200% of the federal poverty guideline (FPG).¹ Among the provisions of the SCHIP legislation is a mandate to assess the program's ability to meet the needs of CSHCN.

The study described here is one method the Women's and Children's Health Section of the North Carolina Division of Public Health is using to assess the ability of NC Health Choice to meet the needs of this special population. In funding this study, the Division supported the inclusion of a sample of Medicaid children in order to examine the difference in experience between children in these two public insurance programs. They also supported the inclusion of a sample of children insured by the State Employees' Health Plan (SEHP). The addition of a sample of children insured by SEHP allows comparison of publicly insured children to children covered by a large private, employment-based insurance program. The State Employees' Health Plan insures a large number of North Carolinians including children of State employees in various government departments, public schools, and universities. Although some State employees in lower income brackets may actually qualify for NC Health Choice, average family income in this group of insured children is higher than that of children in the other insurance groups. The advantage this gives SEHP parents in obtaining health care for their children is acknowledged and the implications of differences in income among the groups of children studied will be discussed.

¹ The Federal Poverty Guideline (FPG) is the income level adjusted for family size that is used to assign poverty status and determine qualification for certain federal and state programs. For example, the 2002 FPG for a family of four is an income of \$18,100 per year. To qualify for North Carolina Health Choice for Children a family's income can not exceed 200% of FPG, i.e., \$36,200 for a family of four.

There are differences in benefits and other plan policies among the three health insurance programs that are important to understanding the results and implications of this study (Table 1).

Table 1: Description of Insurance Plans			
	Medicaid	NCHC	SEHP
ELIGIBILITY			
Income requirements	Varies by age: <1yr: family income \leq 185% FPG 1-5yr: family income \leq 133% FPG 6-18yr: family income \leq 100% FPG	Ineligible for Medicaid and family income \leq 200% FPG	No
Coverage by other insurance allowed	Yes	No	Yes
Term of coverage	1 year, renewable, until age 19 within income guidelines above	1 year, renewable, until age 19 within income guidelines above	Indefinite
COST			
Enrollment fee/premium	No	Yearly if family income >150% FPG, \$50 for one child or \$100 for two or more	Monthly premium for employee's family
Co-payment for svcs	No	Yes, if >150% FPG	Yes
Co-payment for prescriptions	No	Yes, if >150% FPG	Yes
BENEFIT STRUCTURE			
Provider choice	No	Yes	Yes
Referral required for providers other than primary care	Yes	No	No
Pre-approval required for specified services	Yes	Yes	Yes
Dental coverage	Yes	Yes	No

Of particular importance are the financial contributions required of enrollees. While children on Medicaid have no out-of-pocket cost for services, prescriptions, supplies and equipment, there are small costs to children on NCHC with family income greater than 150% of the federal poverty guidelines (FPG) and more substantial cost sharing for children enrolled in SEHP. Other important differences include referral requirements. Children enrolled in NCHC and SEHP can seek services from a specialist directly, but Medicaid recipients must be referred to a specialist by a primary care provider. Finally, there are important differences in provider reimbursement levels, with NCHC levels set equal to those of the SEHP and Medicaid reimbursement being lower.

Using a written survey completed by parents of children with special health care needs identified through ICD-9 diagnosis codes on insurance claims, this study examines the health care and ancillary services that NC parents report that their children with special health care needs require. It also examines which reported health care needs are not being met, and what barriers limit access to needed services. The survey asked about the following types of care: general pediatric care and specialty medical care, dental care, care for attention deficit or attention deficit hyperactivity disorder (ADD/ADHD), mental health or substance abuse care, prescription medications, specific therapies including respiratory, speech, and occupational/physical therapy, home health care, respite care, and durable medical equipment. Parents were given the opportunity to rate their child's health and describe the health problems for which the child receives the most care. They were also asked if their child received services at school because of his or her chronic condition and how satisfied they were with their child's insurance plan.

This report describes differences in health care needs and barriers to care reported by parents of children ages 0 through 17 years covered by the three insurance plans and across different diagnosis categories (described below). Descriptive statistics and qualitative analysis of parental reports are combined to assess the extent to which parents of children with special needs in each of the three health plans are able to obtain care for their children.

METHODS

Sample Selection

Identifying children for inclusion in a survey of children with special health care needs is not simple. Condition-specific registries, such as a birth defect registry, or membership rosters of advocacy/support groups are possible sources of parents and children from which a sample might be drawn. These groups are of limited value for a broader-based study that includes many conditions and parents in various economic circumstances. For this study, children were considered to have a special health care need if they had an insurance claim with a diagnosis that appeared on a list of ICD-9 diagnosis codes indicating a special health care need. The list was developed by the Women's and Children's Health Section Clinical Team in collaboration with the NC Commission on Children with Special Health Care Needs. It was a broad and comprehensive listing of all conditions that might meet the definition of a special health care need (available upon request). After preliminary examination of the frequency of claims for these diagnoses among Health Choice enrollees, minor modifications were made to the list to add specific categories related to perinatal health and delete one that identified many children screened for vision problems but who did not have moderate or severe vision impairment. In addition, the chronic infectious disease category was deleted from the sample frame due to the predominance of children with HIV/AIDS in that small group.

The resultant list of diagnosis codes was divided into five broad groups from which to draw samples. The five diagnosis groups included: 1) asthma, 2) attention deficit and attention deficit hyperactivity disorder (ADD/ADHD), 3) developmental delay, 4) mental health diagnoses except ADD/ADHD, and 5) all remaining diagnoses on the list including cancer, diabetes, juvenile arthritis, heart and other birth defects, among others. This final group is hereafter referred to as the chronic disease group. There were a number of diagnoses of particular interest

but not all had an adequate number of NCHC children (the insurance plan with smallest number of enrollees) with that diagnosis to allow creation of separate samples by diagnosis. For example, there were not enough children with the diagnosis of diabetes to create a separate sample for that group but there were enough with asthma, ADD/ADHD, and all other mental health diagnoses combined to keep each as a separate sample. Children with developmental delay and all other chronic diseases were oversampled compared to their representation in the universe of claims to allow adequate responses regarding important but less frequently used services such as physical therapy or respite care.

Inclusion in the sample was restricted to children who would have been continuously enrolled in their respective health plan for at least one year at the time of survey, or, in the case of infants, since birth. Password-protected electronic files containing the names, addresses, and diagnosis code (or broad diagnosis group in the case of SEHP) for children who had a claim with one of the diagnosis codes during February or March 2001 for children enrolled in Medicaid, October 2000 through March 2001 for NCHC, and January through March 2001 for SEHP were used to draw samples. A longer time frame was needed to obtain an adequate sample of children enrolled in NC Health Choice because of the relatively small number of children enrolled in the program compared to the other insurance plans. Because the population of eligible children studied included some with life-threatening conditions, the names of children in the sample were compared with vital records files supplied by the State Center for Health Statistics to avoid sampling children who were deceased. Lists of sampled children were also compared to avoid selecting multiple children from the same family or the same child multiple times because s/he had health problems that placed them in more than one diagnosis group.

This research project was reviewed and approved by the Committee on the Protection of the Rights of Human Subjects at the School of Medicine, University of North Carolina at Chapel Hill.

Survey Design and Pilot Testing

The survey was developed by Sheps Center staff in an iterative process involving input from staff of the Division of Public Health, Women's and Children's Health Section. Pilot surveys were mailed in March 2001 to the parents of 199 Medicaid children with special health care needs. Ninety-one usable surveys (46%) were returned. Information from these responses was deemed sufficient to inform revision of the survey and after limited revision, the survey instrument was finalized and approved by the Women's and Children's Health Section. Six versions of the 12-page survey were used, each specific to the health insurance plan and gender of the child sampled. Versions of the survey were the same across insurance plans except for questions concerning concurrent health insurance coverage that is not allowed for NCHC enrollees. In addition, some response options were not included for all insurance plans, such as response options regarding prescription co-pays that are not required for Medicaid recipients.

Survey Fielding

The mailed survey was accompanied by a cover letter signed by the investigators, a question and answer sheet explaining the purpose of the study and ensuring confidentiality of responses, and a postage-paid return envelope (examples available on request). The initial mailing also included \$2.00 in cash as a token of appreciation for participation. The survey was

fielded in June 2001 to parents of children enrolled in Medicaid and NC Health Choice. Reminder postcards were sent to non-responders ten days after the original mailing and a second copy of the survey with explanatory materials and return envelope was sent four weeks after the first survey. To increase response rate, a third survey packet was mailed to remaining nonresponders a month after the second survey was sent. Fielding of the survey to parents of SEHP children was delayed until October 2001 to resolve problems with the sample frame and to develop additional explanatory materials for parents in the SEHP sample, particularly those who reside in the Chapel Hill/Carrboro area and who may have been acquainted with the investigators. In all other respects, mailings to the SEHP sample were the same as those to Medicaid and NCHC parents. A toll-free telephone number was noted on all surveys and explanatory materials and parents were encouraged to call if they had questions or concerns about the survey.

Response

Fifteen hundred children were sampled from each insurance plan. Within each insurance group, surveys were sent to the parents of 650 children with a diagnosis in the chronic disease group, 100 children with a developmental delay diagnosis, and 250 children in each of the asthma, ADD/ADHD and mental health diagnosis groups. Response rates were adjusted to account for children who were discovered to be too old for the study (<1%). The survey response rate for all insurance groups combined was 61.6%. Overall and for each diagnosis group, the response rate was highest from parents of children enrolled in NC Health Choice (Table 2).

Table 2: Response Rate, by Insurance Group and Diagnosis Group						
	Medicaid		NCHC		SEHP	
	# of Usable Surveys Received	Response Rate (%)	# of Usable Surveys Received	Response Rate (%)	# of Usable Surveys Received	Response Rate (%)
Total*	825	56	1,015	70	889	59
Asthma	141	57	168	68	133	53
ADD/ADHD	147	60	174	70	131	52
Chronic Disease	354	56	443	72	417	64
Dev Delay	54	54	70	70	58	58
Mental Health	128	53	159	65	142	57
* The total number of surveys received for each insurance plan does not equal the sum of surveys received in each diagnosis group because 10 surveys were returned anonymously and could not be assigned to a diagnosis group.						

Parents of NCHC children were more likely to respond to the survey, but there were no significant differences in the distribution of diagnosis groups across plans in the final analysis sample (Table 3).

Table 3: Diagnosis Group as a Percent of Overall Analysis Sample, by Insurance Plan			
	Medicaid (N=825) %	NCHC (N=1,015) %	SEHP (N=889) %
Asthma	17	17	15
ADD/ADHD	18	17	15
Chronic Disease	43	44	47
Dev Delay	7	7	7
Mental Health	16	16	16
Differences among all diagnosis and insurance groups are NOT statistically significant (p=.640).			

The distribution of children by age did differ by insurance plan (Table 4). The percent of young children is higher in the Medicaid sample due to program eligibility requirements that vary by age. As a result, fewer younger children are enrolled in NC Health Choice, as younger children in a family may qualify for Medicaid and older children qualify for NC Health Choice. The analysis implications of this age distribution will be discussed as appropriate.

Table 4: Age Distribution, by Insurance Group [†]			
	Medicaid (N=825) %	NCHC (N=1,015) %	SEHP (N=889) %
0-5 years	46	18	27
6-11 years	33	47	29
12-17 years	20	35	44
[†] Differences among all age and insurance groups are statistically significant at p<0.01.			

Data Analysis

Analysis data files were constructed using SAS statistical software, version 8.1. All analyses were conducted using STATA statistical software, version 7. Sufficient information was not available from all the health plans to allow calculation of survey weights to adjust the responses of the sample to the universe from which they were drawn. Therefore, unweighted results are presented comparing responses across insurance groups and, less frequently, across diagnosis groups. Statistically significant differences among groups are calculated using the Pearson's Chi-square statistic. Missing responses to individual questions were deleted from the analysis for that question unless stated. Questions with a large number of missing values are noted and implications for interpretation of the data are discussed.

A Special Problem: Identifying Children with Special Needs

As noted above, identifying children for inclusion in a survey of children with special health care needs is problematic. There is no one registry of children with special health care needs. The diagnoses that would indicate a special health care need are extensive and can involve virtually any body system and, sometimes, multiple systems. Programs that serve specific children, e.g., programs for the hearing impaired, support/advocacy groups for parents of children with birth defects or chronic disease, or disease registries such as a cancer registry, are all potential ways to enlist the support of parents of children with special needs, but are limited to their particular health problem. In addition, parents sampled because of membership in an advocacy group may be more informed and proactive about their child's health and health care and thus bias the study results.

Researchers and program administrators have developed screening questions to identify children with special health care needs who could potentially benefit from enhanced services. These questions were added to the joint Medicaid/NC Health Choice application in November 2000. However, no comparable process existed for identifying CSHCN enrolled in the SEHP, so using this screening process was not an option for identifying children for this study. As these screening devices are validated and replicated, they may become valuable tools for identifying children with special health care needs for future studies.

In order to find children with a broad range of diagnoses for this study, health care claims data were used as described in the sample selection section above. There is bias inherent in the use of health care claims to identify a survey sample. First, in order to be included in an insurance claims file, a child must have had at least one encounter with the health care system. Thus, the needs of children with severe access barriers who receive no care at all will not be assessed. While this would be a significant concern if the focus of the study were, for example, healthy children's access to preventive care, we believe it to be less of a concern here. For children in the asthma and developmental delay groups and for many children in the chronic disease group, encounters with the health care system are almost unavoidable. That is not to say, however, that health care use for these groups always occurs in the most appropriate setting such as at the office of a primary care provider versus the emergency room, or that the parent believes that all their child's needs are being met. This sampling strategy is likely to miss children whose ongoing conditions are well controlled and who get care infrequently. It may also miss children with mental health and ADD/ADHD diagnoses who do not receive intensive care for these conditions and have no medical problems for which they seek care.

In addition to missing certain children with special health care needs, using insurance claims to identify a sample can identify children as having a special health care need when they do not. For example, a child may have had a condition on the list of diagnoses but it has resolved or the parent perceives it to have resolved and does not report the condition or use of services related to the condition on the survey. Second, the child may have been taken to the physician to rule out a chronic condition but does not in fact have the condition. Finally, there may be errors in the coding of diagnoses. One way to avoid sampling children who do not have special needs would have been to only sample children with multiple visits. This approach, however, would increase the bias discussed in the previous paragraph, by excluding children with infrequent but nonetheless important need or those who face formidable barriers to care and thus receive little.

It was important to validate as far as possible the success of using claims data as a method for identifying children with special health care needs. Specific questions were included in the survey that asked parents to report the health problems for which their child received care and what diagnosis, if any, their child had been given.

All surveys were reviewed by two project staff members with clinical experience to assign special needs status to children based on comparison of the claim diagnosis and the parent's report of health problems and services needed and used. Sample children were classified into three categories: parent reports the same health problem as the claims diagnosis or a health problem in the same broad group, parent reports a health problem in another broad group, e.g., the child was sampled for a mental health claim but parent reports only a chronic medical problem, and parent reports no chronic health problems (Table 5).

Table 5: Parental Agreement with Health Care Claim Diagnosis, by Insurance Group [†]			
	Medicaid (N=825) %	NCHC (N=1,015) %	SEHP (N=889) %
Parent report agrees with claim diagnosis group	74	75	69
Parent reports health problem in a different diagnosis group	11	7	8
Parent reports no special health care needs	14	17	22
Cannot classify*	<1	<1	<1
[†] Differences among all parental report and insurance groups are statistically significant at $p<0.01$. *The majority of surveys that could not be classified were ones that had been returned anonymously and could not be linked to their claims diagnosis.			

For children on Medicaid and NCHC, more than 80% of parents reported that their child had a health problem that would indicate a need for special health care. Parents of children enrolled in SEHP were more likely to report that their child had no special needs.

Because detailed claims diagnoses were not available for SEHP children, it was more difficult to compare parent report to the claims diagnosis for those children sampled in this insurance group. This lack of detail may partially account for the higher portion of SEHP parents who reported that their child had no problems. It is also possible that SEHP parents, because of their higher socioeconomic status, are more likely to take their children for “rule-out” visits. It is not possible to determine, on the other hand, what portion of SEHP children might actually be healthier by virtue of the advantages that higher socioeconomic status affords a family.

Parental agreement with the claims diagnosis was also compared across the five diagnosis groups (Table 6).

Table 6: Parental Agreement with Health Care Claim Diagnosis, by Diagnosis Group [†]					
	Asthma (N=442) %	ADD or ADHD (N=452) %	Chronic Disease (N=1,214) %	Developmental Delay (N=182) %	Mental Health (N=429) %
Parent report agrees with claim diagnosis group	86	92	63	74	67
Parent reports health problem in a different diagnosis group	2	3	9	13	19
Parent reports no special health care needs	12	5	28	13	13
[†] Differences among all parental report and diagnosis groups are at statistically significant at p<0.01.					

Several factors might explain the difference in agreement observed in Table 6. For parents of children with ADD/ADHD, asthma, and developmental delay, the daily impact of these conditions might make it more likely that a parent would report them. By and large, children in the ADD/ADHD group were older (fewer than 5% were under 6 years old) and may be otherwise healthy, thus leading parents to report this condition as one requiring a lot of care. On the other hand, parents of children in the mental health group may be hesitant to report a mental health condition or simply not see their child's mental health issues as the type of health care need we were seeking. The chronic disease category was quite large and included some conditions that parents might not consider a chronic problem, e.g., conductive hearing loss.

We have chosen to include all survey responses in our analyses. If we limited the analysis to only those children whose parents reported a special health care need, we could introduce further bias if we incorrectly assume that a child was NOT a special needs child, based on some omission of information by the parent. For example, one could interpret a parent's report of only minor health problems or even a parent's leaving the question blank as evidence that the child does not have a special need. However, the parent might not have reported the problem because they did not want to identify their child's condition, were unsure of the medical terminology, or were uncertain how to spell the diagnosis. Similarly, lack of use of services that one would expect a child with a certain diagnosis to need could reflect that the child does not have a special need, but could also reflect that the child did not need such services within the limited time frame we specified or did not have access to services. By including all responses in the analysis, our estimates of health care need and service use for children with special health care needs are conservative.

We acknowledge that the method we used to identify children with special health care needs was broad and likely over-inclusive. However, all children in our sample had a claim with a diagnosis identified as signifying a special need. For certain conditions, our sample likely includes children whose parent does not perceive an ongoing problem or children who, in fact, may not have an ongoing problem, e.g., children with a claim diagnosis code of conductive hearing loss which was due to repeated ear infections and indicative of the need for placement of

tubes to drain the ears. There may be children whose claims were coded by a provider in a way to assure insurance payment but whose parents did not know that this diagnosis was being recorded. Children who have a condition that has been surgically repaired, e.g., a birth defect, or who have successfully adapted to their health problem, may be viewed by their parent as having no health problem. Finally, we assume that there is error in ICD-9 coding on some portion of claims, but cannot determine how consistent that error might be across insurance plans or across diagnosis groups.

RESULTS

Unless noted, results are presented comparing all children in the sample across insurance plans, regardless of claim diagnosis or parental report of diagnosis. Analysis of data for subsets of the survey sample, e.g., children in specific diagnosis groups or of specific ages, follows within each section, as appropriate.

Child's Health Status

Parents were asked to describe their child's health as excellent, good, fair, or poor (Table 7).

Table 7: Child's Health Status, by Insurance Group [†]			
	Medicaid (N=813) %	NCHC (N=991) %	SEHP (N=876) %
Excellent	23	26	45
Good	51	57	46
Fair	23	16	8
Poor	3	2	<1
[†] Differences among all health status and insurance groups are statistically significant at p<0.01.			

Responses varied significantly, across health insurance plans and across diagnosis groups (Table 8). Children covered under the SEHP were more likely to be reported to be in excellent health, and Medicaid children were more often reported to be in fair or poor health.

Table 8: Child's Health Status, by Diagnosis Group [†]					
	Asthma (N=430) %	ADD or ADHD (N=445) %	Chronic Disease (N=1,193) %	Developmental Delay (N=182) %	Mental Health (N=420) %
Excellent	17	41	33	34	30
Good	61	47	49	52	54
Fair	20	11	16	14	14
Poor	2	<1	3	<1	3
[†] Differences among all health status and diagnosis groups are statistically significant at p<0.01.					

Parents of children with asthma were less likely to report that their child is in excellent health. Parents of children with ADD/ADHD were less likely to report that their child is in fair to poor health.

Receipt of Services at School or Day Care

Overall, 34% of parents of children who attend school or day care reported that their child received special services at school because of their health or developmental condition. Percentages differed significantly across diagnosis groups with receipt of services at school reported by parents of 70% of children with developmental delay, 50% of children with ADD/ADHD, 32% of children with a mental health diagnosis, 28% of children with a chronic disease, and 17% of children with asthma.

The likelihood of receiving school-based services also varied significantly by insurance plan, with Medicaid enrollees most likely to use school services (41%) followed by NCHC (36%) and SEHP (26%). The differences among health plans were particularly marked for children in two diagnosis groups. Among children in the asthma group, those covered by public insurance were significantly more likely to receive services at school (21 - 23%) compared to children on SEHP (9%). Among children with a mental health diagnoses, Medicaid enrollees were the most frequent users of school services (51%) compared to NCHC (28%) and SEHP (22%).

General Medical Care

Parents were asked to consider that their child might need medical care by two types of providers: doctors or nurses that their child might see for check-ups, immunizations and common childhood problems (referred to here as “general medical care”) and medical specialists. Parents were instructed to indicate which of these two types of doctors (or clinics) their children saw and answer separate questions for each type of care.

Most parents (97%) reported that their child had a provider for general medical care. Parents were asked to report by type all of the places to which they take their child for general care (Table 9). Responses were aggregated to indicate if the child received care in a single type of medical office or clinic (private, public or hospital) versus care in multiple settings.

Table 9: Site for General Medical Care, by Insurance Group [†]			
	Medicaid (N=775) %	NCHC (N=954) %	SEHP (N=855) %
Private office or clinic only	59	66	76
Health department, community health center, or other community clinic only	11	8	3
Hospital clinic only	16	11	9
Other* or unknown only	<1	<1	<1
Multiple types of places	14	14	11
[†] Differences among all site of care and insurance groups are statistically significant at p<0.01. *>80% of sites in this category that could be classified were either urgent care facilities or chiropractors.			

The majority of all children received general medical care at a single type of provider. Children insured by SEHP were more likely to get their general care in the private sector. Children covered by Medicaid were more likely than children in the other insurance groups to get general care at the health department, a community clinic, or a hospital clinic.

In order to assess unmet need for general care, parents were asked if there had been any time in the previous six months when their child had needed general medical care but could not get it (Table 10).

Table 10: Unmet Need for General Medical Care, by Insurance Group						
	Medicaid (N=805)		NCHC (N=1,000)		SEHP (N=879)	
Could not get needed general care [†]	10%		5%		4%	
<i>For those who could not get care, barriers reported by parents included:</i>						
	Medicaid (N=78)		NCHC (N=54)		SEHP (N=38)	
	Number	%*	Number	%*	Number	%*
	who said yes		who said yes		who said yes	
Insurance would not pay	12	15	13	24	11	29
Couldn't find a provider that would accept insurance	13	17	6	11	2	5
Couldn't find provider that would treat child with my child's condition	3	4	0	0	1	3
No transportation [†]	24	31	6	11	0	0
Office hours were not convenient	23	30	24	44	13	34
Other	21	27	12	22	17	45
[†] Differences across insurance groups are statistically significant at p<0.01. *Columns may sum to >100% because parents could report multiple barriers.						

Overall, 6.5% of parents reported having difficulty getting general medical care for their child in the previous six months. Unmet need for general medical care was most commonly reported for children with Medicaid with 10% of that group needing care they could not get. In addition to having more problems getting general medical care, parents of children on Medicaid were more likely to report difficulty finding a doctor willing to take their insurance and difficulty getting to a provider. The most frequently cited reason for unmet need for general medical care for NCHC children was provider office hours, while almost half of SEHP parents reported “other” problems such as problems getting appointments and other barriers which included lack of funds for the deductible or co-payment.

For children with Medicaid and NCHC, there were no significant differences in unmet need across diagnosis groups. For children insured by SEHP most of the unmet need was among children with either developmental delay or mental health diagnoses. It is important to keep in

mind, however, that for all children in SEHP the portion with unmet need was only 4% (38 children) with even smaller numbers of SEHP children with unmet need in any given diagnosis group.

Specialty Medical Care

Among all children, almost half (45%) received care from one or more medical specialists. There were significant differences across health plans. SEHP children were significantly more likely to receive medical specialist care (53%) compared to Medicaid children (41%) and NCHC children (42%).

There were also significant differences in the likelihood of seeing of a medical specialist across diagnosis groups, with children in the chronic disease group most likely to see a specialist (63%), followed by those with developmental delay (40%), and asthma (39%). Only 29% of children in the mental health diagnosis group and 21% of children in the ADD/ADHD group received care from a medical specialist. Although respondents were given detailed instructions to answer questions regarding care for ADD/ADHD and mental health in sections specifically covering those health care needs, handwritten comments in the surveys suggest that some ADD/ADHD or mental health care may have been reported as specialty medical care. It is not possible to determine the extent to which such care was erroneously reported by parents of children in those two groups. However, for the majority of children in the ADD/ADHD and mental health groups who were reported to have received medical specialty care, parents did report another diagnosis, such as diabetes, consistent with the need for a medical specialist.

The majority of parents of children receiving medical specialty care reported that their child only had only one specialist (61%), while 25% reported that their child saw two different kinds of specialists. The remaining 14% of parents reported from three to eight different types of specialists. Location of specialty care did not vary significantly across insurance plans, likely reflecting restrictions in the locations where such care is offered (Table 11).

Table 11: Site for Medical Specialty Care, by Insurance Group			
	Medicaid (N=326) %	NCHC (N=394) %	SEHP (N=455) %
Private office or clinic only	47	51	53
Health department, community health center, or other community clinic only	4	3	<1
Hospital clinic only	34	33	33
Other or unknown only	1	1	<1
Multiple places	14	12	13
Differences among all site of care and insurance groups are NOT statistically significant (p=0.110).			

There were significant differences in specialist location across the diagnosis groups, with children with chronic disease more likely than children in other diagnosis groups to receive

services at a hospital clinic, and children with developmental delay more likely to receive medical specialty care in multiple locations (Table 12).

Table 12: Site for Medical Specialty Care, by Diagnosis Group [†]					
	Asthma (N=161) %	ADD or ADHD (N=92) %	Chronic Disease (N=732) %	Developmental Delay (N=69) %	Mental Health (N=118) %
Private office or clinic only	69	76	43	45	57
Health department, community health center, or other community clinic only	5	7	1	0	6
Hospital clinic only	14	10	43	30	21
Other or unknown only	2	0	<1	0	<1
Multiple places	11	8	12	25	15
[†] Differences among all site of care and diagnosis groups are statistically significant at p<0.01.					

Overall, about the same percentage of parents reported that their child had unmet need for specialist care in the last six months (7%) as had reported unmet need for general care (Table 13).

Table 13: Unmet Need for Specialty Medical Care, by Insurance Group						
	Medicaid (N=795)		NCHC (N=985)		SEHP (N=868)	
Could not get needed specialty medical care [†]	10%		6%		5%	
<i>For those who could not get care, barriers reported by parents included:</i>						
	Medicaid (N=79)		NCHC (N=53)		SEHP (N=42)	
	Number who said yes	%*	Number who said yes	%*	Number who said yes	%*
Insurance would not pay [‡]	13	16	12	23	17	40
Couldn't find a specialist who would accept insurance [‡]	19	24	11	21	2	5
Regular doctor needed to refer child but would not [†]	25	32	10	19	3	7
Couldn't find specialist for the care child needed	11	14	9	17	6	14
No transportation [†]	17	22	4	8	0	0
Office hours were not convenient	10	13	5	9	5	12
Other [‡]	11	14	13	24	14	33

[†]Differences across insurance groups are statistically significant at p<0.01.
[‡]Differences across insurance groups are statistically significant at p<0.05.
*Columns may sum to >100% because parents could report multiple barriers.

Once again, children covered by Medicaid were more likely to have had difficulty obtaining specialist care. Parents of children on both types of public insurance were more likely than parents of children covered by SEHP to report having difficulty finding a provider who would take the child's insurance. Medicaid parents were also more likely to report not being able to get a referral for specialty care. This finding is consistent with the fact that Medicaid is the only insurance program of the three studied that requires enrollees to obtain a referral to a specialist from a primary care provider. However, even for NC Health Choice and SEHP children, there may be specialists who require a referral before they will see a new patient, regardless of the requirements of the insurance plan. Although the percentage of children with a specialty care access problem was smaller for SEHP children, they were more likely to be unable to access specialty medical services because insurance would not pay for them or because of other barriers which included miscellaneous problems with appointments. Finally, transportation was again reported as a problem for Medicaid parents.

Use of the Emergency Room

Parents were asked if they had taken their child to the emergency room (ER) in the previous six months, and, if so, how many times. Overall, 24% of children had made at least one ER visit. There were significant differences in ER utilization across insurance groups. Children covered by Medicaid were the most likely to have used emergency room services (34%), followed by NCHC (25%) and SEHP (15%). Among diagnosis groups, children in the asthma group were most likely to have used the ER (35%), followed by those with other chronic disease (25%), developmental delay (24%), mental health conditions (22%), and ADD/ADHD (16%).

For their child's most recent visit to the ER, parents were asked to describe the health problem for which they sought care and circle the reason(s) they went to the ER, e.g., it was an emergency, their regular doctor's office was closed, etc. There were no significant differences across health plans as to the reasons why parents reported they took their child to the emergency room. Just over one-half (52%) stated that it was an emergency, 19% reported that they had been instructed to go to the emergency room by their child's regular doctor or provider, and 47% responded that their child's regular doctor's office or clinic was closed. We aggregated the responses to this series of questions to create a measure of "appropriateness" of care. Parents who indicated that they went to the ER because it was an emergency and/or because a health care provider told them to go there were considered to have made an appropriate ER visit. Overall, 65% of ER visits were classified as appropriate. The remaining 35% of parents did not report either being sent to the ER by their regular provider or that it was an emergency, but stated that their child's most recent ER visit was because their regular doctor was closed or was for another reason such as not knowing where else to go or needing care when they were out-of-town. These responses may indicate a non-emergent situation and could be considered inappropriate ER use. While the percentage of children who made an ER visit regardless of reason did differ by health plan, among those who went, the percent reported to have been taken there for a non-emergent problem as defined above did not differ across health plans.

Health care providers and insurers are particularly interested in the use of the emergency room as a marker of inadequate access to health care. Conditions known as ambulatory care sensitive conditions are sometimes examined to assess how well children and adults are getting disease treatment and education to allow them to manage their disease on an outpatient basis and avoid costly hospitalization and use of the emergency room. Asthma is one such ambulatory

care sensitive condition. Hospitalization was not assessed in this study but use of the ER by this group of children can be described.

As noted above, children selected for the study because they had an insurance claim for asthma were more likely than children in other diagnosis groups to have had an ER visit. In addition, among children chosen because of their asthma diagnosis, those insured by Medicaid were significantly more likely than comparable children insured by NCHC or SEHP to have had an ER visit (46%, 33% and 25%, respectively).

We further classified an ER visit as being asthma-related if parents listed the reason for seeking care as asthma, reactive airway disease, or specific respiratory symptoms that might indicate asthma including wheezing or difficulty breathing. This classification of an ER visit as asthma-related is likely conservative because asthma might be the underlying condition that prompts a parent to seek ER care for a child with other respiratory problems. Among the parents of children in the asthma diagnosis group who responded that their child had made an ER visit within the specified timeframe, 51% reported this visit to be asthma-related. Children in other diagnosis groups also made visits that we classified as asthma visits, ranging from 11% of children in the ADD/ADHD group to 5% of children in the mental health group.

In general, asthma was a large component of emergency room use reported by this group of parents. Eighteen percent (18%) of parents, regardless of the child's claim diagnosis, reported that their child's most recent emergency room visit was for asthma. Two-thirds of this use was by children in the asthma diagnosis group, but one-third was not, supporting the notion that many of the children in our sample have multiple health problems and could have been in more than one diagnosis group.

Prescription Medication

Parents were asked if their children had been given a prescription for medication in the past six months (Table 14).

Table 14: Prescription Medication and Medical Equipment or Supplies, by Insurance Group			
	Medicaid (N=811-820)* %	NCHC (N=1,003-1,004)* %	SEHP (N=884-886)* %
Given a prescription in last 6 months	89	88	85
<i>Of those needing prescription medicine, % who could not get it</i>	7	4	7
Needed medical equipment or supplies [†]	27	18	21
<i>Of those needing equipment or supplies, % who could not get them[†]</i>	14	25	11
*Number of parents responding (N) varies by question. [†] Differences across insurance groups are statistically significant at p<0.01.			

Almost all of the children in the sample (87%) had been given a prescription for medication at least once in the previous six months, with children in the asthma (94%) and ADD/ADHD (96%) groups more likely than children in other groups to have been prescribed medication. Among all children who were prescribed medication, 6% were unable to get the prescription filled, and the percent with unmet prescription needs did not differ significantly by insurance plan.

The most common reason parents of children enrolled in Medicaid and NCHC reported not being able to get the prescription filled was that their child's insurance would not pay for the particular medicine. For children enrolled in SEHP, the fact that the insurance only covered part of the cost and the parent did not have the rest was the most commonly reported barrier to obtaining medication.

Medical Equipment and Supplies

Parents were also asked whether their child had needed any special medical equipment or supplies in the previous six months (Table 14). Overall, 22% of parents reported that their child needed such items. Children in the asthma diagnosis group were most likely to have needed equipment or supplies (41%), followed by children in the chronic disease group (27%). There were significant differences across insurance groups in the percent of children with both need and unmet need. Children enrolled in Medicaid were more likely to have needed equipment or supplies, but NCHC children were more likely to be unable to get their needs met. For all children combined, the most frequent barrier to receipt of the needed items was that their insurance did not cover the equipment the child needed. More than three-quarters (80%) of SEHP parents reporting unmet need reported this barrier followed by 70% of Medicaid parents and 64% of NCHC parents.

Like most questions in the survey that asked parents to recall health care needs, the time frame specified for needing equipment and supplies was the past six months. This question likely underestimates the need for special equipment by children with special health care needs, particularly durable medical equipment that does not need frequent replacement or replenishment. The types of medical equipment or supplies reported as needed but not obtained frequently were for care for asthma and diabetes. Among the 98 parents reporting unmet need, one-fourth said that the type of supply or equipment their child needed but could not get was for asthma care, usually a nebulizer (11 Medicaid, 11 NCHC, and 3 SEHP). Although there are many fewer children with a diagnosis of diabetes in the sample, another one-fourth of parents who reported an unmet need for equipment or supplies specifically mentioned diabetic supplies such as test strips and/or insulin needles (4 Medicaid, 17 NCHC, and 3 SEHP.) Hearing aids were the third most commonly reported unmet need (11%), particularly for NCHC and SEHP children.

Specialized Therapies

Children with special health care needs may need other types of care such as physical, speech, occupational or respiratory therapy to help them meet developmental milestones or adapt to limitations caused by birth defects, disease, or injury. The need for many of these therapies may not be great in the general population but may be critical for CSHCN. The survey sample was chosen to ensure representation of a group of children who might need such therapies to

assess how well their insurance plans were meeting their needs. The survey included questions about three types of therapy: respiratory, speech, and physical/occupational therapy combined in one question. The follow-up questions regarding unmet need asked not if the child was able to get any of the type of therapy in question but if the child was able to get all the therapy the parent thought that he or she needed (Table 15).

Table 15: Specialized Therapies, by Insurance Group			
	Medicaid (N=813) %	NCHC (N=1,002-1,003)* %	SEHP (N=876-882)* %
Needed respiratory therapy in previous 6 months [†]	19	12	9
<i>Of those needing RT, % who could not get all they needed</i>	4	2	5
Needed speech therapy in previous 6 months [†]	17	13	11
<i>Of those needing ST, % who could not get all they needed[†]</i>	25	14	33
Needed physical or occupational therapy in previous 6 months [†]	13	7	12
<i>Of those needing PT or OT, % who could not get all they needed</i>	14	18	23
*Number of parents responding (N) varies by question.			
[†] Differences across insurance groups are statistically significant at $p \leq 0.01$.			

Respiratory Therapy

For all children combined, 13% were reported to have needed respiratory therapy services in the previous six months (Table 15). Medicaid children were significantly more likely to have needed respiratory therapy than were children on other health plans. Although the diagnosis group most likely to have needed respiratory therapy was the asthma group (43%), there were children in all other diagnosis groups with reported respiratory therapy needs. There were no differences across health plans for the small number of children (13 total) who could not get all the respiratory therapy they needed. One-half of these children were in the asthma diagnosis group. The primary reasons the child could not get all respiratory therapy services needed was that insurance would not pay for the care or the physician would not refer the child for care.

Speech Therapy

Thirteen percent (13%) of all parents reported that their child needed speech therapy in the previous six months (Table 15). Once again, a higher percentage of children on Medicaid needed this therapy, followed by children on NCHC and SEHP.

Children in all five diagnosis groups were reported to need speech therapy, but the children most likely to need this service were those with a diagnosis of developmental delay, the

group that included the diagnosis code for speech delay. Almost 70% of children in the developmental delay group were reported to need speech therapy.

Almost one-quarter (23%) of children who needed speech therapy were unable to get all the therapy they needed. Unmet need for speech therapy varied by health plan and was highest for children covered by the SEHP. The predominant reasons children could not get all the care they needed varied across health plan. For children in SEHP, the most frequently reported reason was that insurance would not pay at all or would not pay for speech therapy for a child with their child's diagnosis. SEHP parents also reported that the school was supposed to provide the therapy but did not. For Medicaid and NCHC children, reported barriers were limits on the number of covered visits, inability to find someone to provide the services, and failure of the school to provide the therapy. The majority of children who needed but were unable to get speech therapy were in either the chronic disease group (35%) or developmental delay group (32%).

Physical or Occupational Therapy

The overall need for physical or occupational therapy (PT/OT) was similar to that for other therapies, with 11% of parents reporting such a need in the last six months (Table 15). Children with Medicaid and SEHP were significantly more likely than children on NCHC to have needed this care. Again, the diagnostic group most likely to report needing these services was developmental delay (35%).

Overall, among children who needed physical or occupational therapy services, 19% could not get some or all of the needed services. Differences across insurance groups were not significant, and the number of children with access barriers was small. Parents of children in the chronic disease group were more likely than parents in other groups to report that their child could not get needed PT/OT service (46% of all children with unmet need). Among the 52 children who could not get PT/OT, the most common barrier was a limit to the number of visits paid by their insurance (11 children), the parent could not find a place to take their child (10 responses), that the parent could not afford the services (7 responses, 6 of which were children covered by SEHP), and that the school was supposed to provide the services but did not (7 responses).

Home Health Care and Respite Care

Home health care and respite care may be important for the family of a child with special health care needs, but beyond the family's economic reach. Home health services may help avoid continued hospitalization or trips to the doctor's office for care. Respite care may give families a needed break from the ongoing and frequently time-consuming care for a chronically ill or disabled child. Parents were asked if they needed each of these services and, if so, if all of their needs had been met (Table 16).

Table 16: Home Health Care and Respite Services, by Insurance Group			
	Medicaid (N=805-808)* %	NCHC (N=1,002-1,005)* %	SEHP (N=881-883)* %
Needed home health care in previous 6 months [†]	4	1	2
<i>Of those needing home health, % who could not get all they needed</i>	21	22	24
Needed respite care in previous 6 months [†]	5	2	4
<i>Of those needing respite care, % who could not get all they needed</i>	58	50	56
*Number of parents responding (N) varies by question.			
[†] Differences across insurance groups are statistically significant at $p \leq 0.01$.			

Only 2% of all children in the sample were reported to need home health services. Children on Medicaid were significantly more likely to need these services although the proportion in that group was still small (4%). Of those who needed home health care, about one-quarter could not get it and there were no differences across insurance groups. Among the 13 children who could not get these services, the predominant reasons were that the insurance would not pay for the services at all, or they were not covered for the child's specific diagnosis.

The need for respite care was equally small, with only 4% (N=94) of all parents reporting such need in the last six months. Although the number of parents reporting the need for respite care was small, over one-half of them were unable to get this care, with no significant differences across insurance plans. While 19 parents reported that they had been unable to find a caregiver, 10 parents of children enrolled in SEHP were unable to get this care because the plan did not cover it, and 5 parents of Medicaid children could not get all the care needed because Medicaid limited the amount of services. Other barriers reported by parents included uncertainty about these services and how to obtain them.

Dental Care

In this survey, need for dental care, unlike need for more specialized services, was assumed and not queried. Parents were asked instead where they take their child for dental care. For children younger than six years, it is not possible to determine if a child did not have a dental provider because of insurance limitations or provider barriers, or because the parent did not perceive a need for care. Analysis of data regarding use of and access to dental services is, therefore, limited to children six years of age and older.

Unlike the two public insurance programs, the SEHP does not include dental services as a covered benefit. Responses for these children are still included in the analysis of dental care to provide a comparison group and give a sense of the relative access that comes with a higher income. This is an important issue in this cross-insurance comparison, and one that, no doubt, accounts for some of the better access reported for SEHP children for other services. However, the contribution of dental insurance to the better access to dental care seen for children covered by SEHP cannot be measured. Separate dental insurance is an option for purchase by State employees but the survey did not include questions specific to whether or not SEHP parents had purchased this insurance.

Table 17: Site of Dental Care, Children 6 through 17 Years of Age [†]			
	Medicaid (N=444) %	NCHC (N=832) %	SEHP (N=649) %
Child never goes to the dentist	9	7	3
No regular place or multiple places	14	9	2
Private office or clinic only	55	71	93
Health department, community health center, or other community clinic only	18	10	<1
Hospital dental clinic only	2	1	2
Other only or cannot classify	2	1	<1
[†] Differences among all site of care and insurance groups are statistically significant at p<0.01.			

Even though all children on Medicaid and NCHC have dental coverage, and many children on SEHP probably do not, a higher percentage of children on public insurance never go to the dentist (Table 17). Almost one in ten children in the Medicaid sample do not see a dentist. Medicaid parents were also more likely to report that their children had no regular site for dental care or received care at multiple places.

Parents were asked whether there were any times in the previous six months that they thought their child needed dental care but could not get it (Table 18).

Table 18: Unmet Need for Dental, by Insurance Group, Children 6 through 17 Years of Age						
	Medicaid (N=438)		NCHC (N=818)		SEHP (N=647)	
Could not get needed dental care [†]	23%		18%		7%	
<i>For those who could not get care, barriers reported by parents included:</i>						
	Medicaid (N=100)		NCHC (N=142)		SEHP (N=46)	
	Number who said yes	%*	Number who said yes	%*	Number who said yes	%*
Insurance would not pay [†]	21	21	52	37	29	63
Couldn't find a dentist who would accept insurance [†]	61	61	65	46	1	2
Couldn't find a dentist who would take children	10	10	9	6	0	0
Couldn't find a dentist who would take children with child's condition	3	3	5	4	3	7
No transportation [†]	14	14	5	4	0	0
Office hours were not convenient	9	9	9	6	2	4
Other [†]	18	18	21	15	25	54

[†]Differences across insurance groups are statistically significant at p≤0.01.

*Columns may sum to more than100% because parents could report multiple barriers.

There were significant differences in unmet need across health plans. Only 7% of parents of SEHP children reported a problem accessing dental care while 18% of NCHC and 23% of Medicaid children had unmet dental care needs. Among those who could not get needed dental care, barriers varied across plans. Medicaid parents continued to report transportation barriers when trying to obtain care for their child, but by far the most commonly cited reason for unmet dental care need for Medicaid children was that the parent could not find a dentist who would accept Medicaid. Lack of acceptance of the child's insurance was also a problem for those on NCHC, although not quite as great. For SEHP, most parents cited no insurance coverage as a barrier to care. Barriers listed under "other" for that group included not being able to afford care and, less frequently, difficulty getting an appointment.

Parents were also asked to report the type of dental care they could not obtain for their child. Their open-ended responses have been categorized as shown in Table 19.

Table 19: Dental Care Needed but Not Obtained, Children 6 through 17 Years of Age			
	Medicaid (N=100) %*	NCHC (N=146) %*	SEHP (N=46) %*
Routine preventive dental care [‡]	38	34	57
Acute dental care	22	17	17
Dental extraction	8	14	7
Orthodontia	18	27	24
Miscellaneous	6	12	2
Cannot classify	17	9	13
*Columns may sum to more than 100% because parents could list multiple dental care needs.			
[‡] Differences across insurance groups are statistically significant at $p \leq 0.05$.			

There were significant differences across insurance groups in the type of dental care needed but not obtained. Fewer parents of SEHP children reported unmet need for dental care, but they were more likely than parents in other insurance groups to report that their child needed but could not get routine preventive care. Other needed services reported by all insurance groups included acute care and orthodontia.

ADD/ADHD Care

All parents surveyed were asked if their child had received care for ADD/ADHD and where they got that care (Table 20). Because children with that diagnosis were sampled specifically to assess how well their needs were met, results are presented for children in the ADD/ADHD group separately from all other children in the sample.

Table 20: Provider for ADD/ADHD Care, by Insurance Group, for Children in ADD/ADHD Sample and All Other Children						
	ADD/ADHD Sample			All Other Children		
	Medicaid (N=146) %	NCHC (N=163) %	SEHP (N=130) %	Medicaid (N=642) %	NCHC (N=799) %	SEHP (N=720) %
Received care for ADD/ADHD in last 6 months	90	94	92	15 [†]	16 [†]	10 [†]
<i>For those who received care, where care was obtained (%)^{§‡}</i>						
	(N=131) %	(N=162) %	(N=118) %	(N=93) %	(N=131) %	(N=72) %
Pediatrician or family doctor only	31	43	44	9	21	14
Specialist only – psychologist, psychiatrist or other MD	30	23	32	32	37	53
Public health department or community clinic only	17	8	4	32	15	0
Other type of provider only	0	1	1	3	2	10
Multiple types of provider	22	25	19	24	25	24
[†] Differences among % who received care are statistically significant at $p \leq 0.01$ for the “All Other Children” group only. [‡] Differences among site of care and insurance groups are statistically significant at $p \leq 0.05$ for the ADD/ADHD sample. [§] Differences among site of care and insurance groups are statistically significant at $p \leq 0.01$ for the “All Other Children” group.						

Ninety percent (90%) or more of children sampled because of a health insurance claim indicating ADD or ADHD were reported by their parents to have received care for ADD/ADHD in the past six months. In addition, 10 to 15% of children in the other diagnosis categories, primarily mental health and developmental delay, also needed such care during the specified timeframe. A higher portion of children on public insurance in other diagnosis categories needed care for ADD/ADHD than did similar SEHP children.

There were not significant differences in the site of care for children in the ADD/ADHD group but there were for children in all other groups combined. For children in the ADD/ADHD sample group, 75 to 80% got their ADD/ADHD care at a single site. Children with Medicaid were more likely to have received care at a health department or community clinic. Among children with multiple providers, 76% got care from their pediatrician or family doctor and one other provider. Differences in site of care across insurance groups were more pronounced for children who were not sampled for ADD/ADHD, with fewer of these children in each insurance group receiving care from their primary care provider. As was seen for medical care, Medicaid children were more likely to receive care in the public sector.

All parents, including those whose children had not received care for ADD/ADHD in the past six months, were asked if their child had needed ADD/ADHD care in the past six months that they had been unable to get (Table 21).

Table 21: Unmet need for ADD/ADHD Care, by Insurance Group, for Children in ADD/ADHD Sample and All Other Children						
	ADD/ADHD Sample			All Other Children		
	Medicaid (N=143) %	NCHC (N=171) %	SEHP (N=130) %	Medicaid (N=614) %	NCHC (N=762) %	SEHP (N=691) %
Needed care for ADD/ADHD but could not get it [†]	16	8	5	7	4	2
<i>For those who could not get care, the reasons were:</i>						
	(N=23) %*	(N=13) %*	(N=7) %*	(N=43) %*	(N=27) %*	(N=11) %*
Insurance would not pay	29	0	29	2 [§]	31 [§]	36 [§]
Could not get referral needed	14	8	0	2	0	0
Insurance pays for limited number of visits	5	25	14	7	19	9
Couldn't find place for care	38	33	0	31	12	18
No transportation	10	8	0	14	0	0
Office not open at convenient time	14	0	0	10	8	0
Child would not go	0	0	14	2	0	0
Other	33	42	71	45	62	45
[†] Differences among insurance groups are statistically significant at $p \leq 0.01$ for both ADD/ADHD sample and the "All Other Children" group. [§] Differences across insurance groups are statistically significant at $p \leq 0.01$ for the "All Other Children" group only. *Columns may sum to >100% because parents could list multiple barriers.						

Few parents reported that their child needed ADD/ADHD care but could not get it, including 10% (N=43) in the ADD/ADHD diagnosis group and 4% of children in all other diagnosis groups combined. There were significant differences across health plans for each subset of children, with Medicaid children more likely to be reported to have unmet need than children with NCHC and SEHP, regardless of diagnosis group.

The number of parents reporting unmet need for ADD/ADHD care was small for all insurance and diagnosis groups, making it difficult to detect statistically significant differences for specific barriers among groups of children. Many parents wrote in a barrier under "other" and listed such things as no available appointments, parental uncertainty about whether to take child for care, not wanting to have the child labeled, or issues with caregivers.

Mental Health/Substance Abuse Care

Like the section regarding ADD/ADHD services, all parents surveyed were asked if their child received care for mental health or substance abuse conditions in the past six months and where they got that care (Table 22). Again, results are reported separately for children selected for inclusion in the mental health group and for all other children.

Table 22: Provider for MH/SA Care, by Insurance Group, for Children in MH/SA Sample and All Other Children						
	MH/SA Sample			All Other Children		
	Medicaid (N=126) %	NCHC (N=156) %	SEHP (N=140) %	Medicaid (N=668) %	NCHC (N=832) %	SEHP (N=714) %
Received care for MH/SA in last 6 months	60	66	60	8	8	7
<i>For those who received care, where care was obtained (%)[†]</i>						
	(N=73) %	(N=103) %	(N=84) %	(N=50) %	(N=69) %	(N=51) %
Community program only	74	38	6	58	39	14
Private psychiatrist or psychologist only	19	51	73	36	49	73
Other type of provider only	1	1	7	4	3	8
Multiple types of provider	5	10	14	2	9	6
[†] Differences among site of care and insurance groups are statistically significant at $p \leq 0.01$ for both the MH/SA sample and “All Other Children” group.						

Only 62% of all parents of children in the mental health diagnosis group reported that their child had received treatment or counseling for mental health conditions or substance abuse in the previous six months with no significant differences across health plans. Although all of these children were sampled because of an insurance claim with a mental health or substance abuse diagnosis, it is possible that this diagnosis appeared on a claim for a medical care visit. It is also possible that parents under-report the use of mental health/substance abuse services. Eight percent (8%) of children in the other four diagnosis groups combined also received this type of care. For children in the “all other children” category, parents of children in the ADD/ADHD groups (23%) and developmental delay group (18%) were more likely to report that their children had received mental health or substance abuse care.

Most (>85%) of the children in the mental health diagnosis group who had received counseling or treatment had received these services from a single provider. Children covered by Medicaid were more likely to use a community mental health or substance abuse program (74%) compared to children on NCHC (38%) and SEHP (6%). SEHP children, on the other hand, were far more likely to go to a private psychiatrist’s or psychologist’s office.

Again, all parents, not just those who reported that their child had used mental health or substance abuse services, were asked if their child had needed services they could not get. Parents of children in the mental health diagnosis group were more likely to report that their child needed treatment or counseling for mental health or substance abuse that they could not get although only one group (Medicaid children sampled for a MH/SA diagnosis) exceeded 10% (Table 23).

Table 23: Unmet Need for MH/SA Care, by Insurance Group, for Children in MH/SA Sample and All Other Children						
	MH/SA Sample			All Other Children		
	Medicaid (N=121) %	NCHC (N=149) %	SEHP (N=133) %	Medicaid (N=644) %	NCHC (N=811) %	SEHP (N=693) %
Needed MH/SA care but could not get it	12	6	9	4	3	2
<i>For those who could not get care, the reasons were:</i>						
	(N=14) %*	(N=9) %*	(N=12) %*	(N=22) %*	(N=20) %*	(N=13) %*
Insurance would not pay	7	22	25	9	15	0
Could not get referral needed	0	0	0	9	0	0
Insurance pays for limited number of visits	21	33	33	5 [†]	15 [†]	38 [†]
Couldn't find place for care	0	22	8	23	10	15
No transportation	21	0	0	27 [†]	0 [†]	0 [†]
Office not open at convenient time	7	0	17	14	10	15
Child would not go	14	22	17	5	25	8
Other	43	44	33	36	45	38
*Columns may sum to >100% because parents could report multiple barriers. †Differences across insurance groups are statistically significant at p≤0.05 for the "All Other Children" group only. ‡Differences across insurance groups are statistically significant at p≤0.01 for the "All Other Children" group only.						

There were no statistically significant differences in barriers reported across insurance plans with the exception of transportation, which is only a significant barrier for Medicaid children sampled for other diagnoses. In addition, a limit to the number of visits covered was a significant barrier for SEHP children sampled for other diagnoses. As was seen with other questions regarding unmet need for care, the number of children with unmet need for MH/SA may be too small to detect other statistically significant differences. Children with NCHC and SEHP were more likely to report not getting services because their insurance would not pay. Parents in all insurance groups reported that the limit on the number of covered visits was a barrier. One-third to almost one-half of parents reported "other" barriers including problems getting appointments and dissatisfaction with care being received.

Case Management/Care Coordination

A section about case management/care coordination was included in the survey. Case management/care coordination was briefly explained and parents were asked to complete one set of three questions if their child had a case manager or another set of two questions if s/he did not. Overall, 11% of parents reported that their child had a case manager, 83% responded that s/he did not, and 6% did not answer the question. The large number of parents who did not answer this question and the problems that parents had completing the questions in each series lead us to believe that these questions were difficult to answer and that some parents were still unsure about which services we were querying. Information from these questions must be interpreted with caution.

For Children with Case Managers

Parents of Medicaid children were significantly more likely to report that their child had a case manager than were parents of children on NCHC and SEHP (20%, 8%, and 6%, respectively.) Part of the difference among plans can be explained by the age distribution among the insurance plans. The Medicaid sample includes more younger children and some case management programs are available only for younger children. For children older than 5 years, however, there were still significant differences in the percentage of children reported to have a case manager, with Medicaid children still more likely to get these services. In anticipation that parents might think that we were inquiring about their Department of Social Services caseworker, the survey specifically instructed respondents that these were not the services in question. Handwritten comments on the survey suggest, however, that some confusion still existed, and it is possible that the erroneous reporting of DSS caseworkers as case managers accounts for some of the differences across insurance plans.

Specific agencies or programs that provide case management services were listed and parents were asked to indicate for which agency or program their child's case manager worked. One-third of Medicaid parents listed Child Service Coordination as providing case management, another quarter were unsure, 21% listed a Developmental Evaluation Center and 20% listed "other" agencies, frequently the Department of Social Services, a mental health agency, or multiple agencies.

NCHC parents were more likely to be unsure which agency or program provided case management (48%) or list Child Services Coordination and "other" including the Department of Social Services. SEHP parents, on the other hand, were more likely to report CAP-MR/DD (23%), Child Service Coordination (23%) and "other" (25%) as providing these services. It is important to keep in mind that the overall number of NCHC and SEHP children receiving case management services is small (84 and 53, respectively) and the number in any one agency or program category is even smaller.

The areas in which case managers helped parents were similar across insurance groups, with two exceptions. SEHP parents were less likely to report receiving help understanding their child's insurance and NCHC parents were less likely to report receiving help finding programs to help their family. It is important to note that parents were not asked if they needed assistance in each area but only if they received assistance. Thus, these data do not measure need for services nor if need has been met.

More generally, parents whose children had case managers reported if the case manager was helpful to them all, some, or none of the time (Table 24).

Table 24: Case Manager Provides the Assistance Needed, by Insurance Group			
	Medicaid (N=159) %	NCHC (N=81) %	SEHP (N=51) %
All of the time	70	59	65
Some of the time	23	31	31
Never	6	10	4
Differences among all satisfaction levels and insurance groups are NOT statistically significant (p=.347).			

Parents of children on Medicaid were more likely to report getting help from their case manager all of the time. Parents on NCHC were more likely to report never getting help. No differences were statistically significant.

For Children without Case Managers

We asked the 83% of parents who reported that their child did not have a case manager whether they had tried to get a case manager for their child. The most common response was that the parent had never heard of case managers, with Medicaid and NCHC parents significantly more likely to so respond compared to SEHP (69%, 67%, and 50%, respectively). Over half (56%) of the parents of children in the SEHP responded that their child didn't need a case manager, compared to only 34% of Medicaid and 40% of NC Health Choice. Only 4% of all parents responded that they did not think they could get a case manager if they tried. Lack of insurance coverage for case management was rarely reported as a barrier by parents in any insurance group. There were also 16 parents who reported that their child had had a case manager in the past. There were no significant differences across diagnosis groups for any reasons that parents reported that their child did not have a case manager.

Parents of children without case managers did report that they received informal help from others in arranging their child's care. Overall, 23% received help from other family members, 9% reported that someone at their child's doctor's office helped, and 7% reported help from friends, parents of a child with a similar problem, or some other person. A very small number of parents reported that they received help from their child's school (18 respondents) or from a mental health counselor or organization (11 parents).

Parental Assessment of Their Child's Insurance

Other Insurance Coverage

For some children, the insurance plan from which they were sampled for this study is not their only form of health insurance. Most Medicaid children (91%) had no additional insurance. Parents of 48 children with Medicaid (6%) had purchased additional coverage for their children. Nine parents also reported that their child was no longer on Medicaid.

Among children in the SEHP group, 84% had no other form of coverage. Two percent of parents had additional coverage for their children through work at no cost and 5% purchased additional insurance for their children. Four percent (4%) reported that their child also had Medicaid. We did not ask about dental insurance specifically but a few parents of children in the SEHP group (11 parents) did report that their child also had dental insurance. There are likely more SEHP children with this coverage. Eleven parents reported that their child was no longer covered by SEHP. Questions about other insurance were not asked of parents of children on NCHC, which does not allow other insurance coverage.

Written Information and Satisfaction with Coverage

Parents were asked if the written information they received about their child's insurance was easy to understand and if it was not, how it was unclear (Table 25). Fewer than 10% of parents of children with public insurance expressed difficulty with written information about the

insurance while more than twice that percentage of parents with children on SEHP reported difficulty. Among parents who described a problem with the written material they had received, common problems reported by parents of children on Medicaid and NCHC included a need for information in another language (usually Spanish) or that they had not received written information. For SEHP parents, problems were that the information was too complex, vague, or confusing, that they had trouble understanding the explanation of a particular benefit, or that cost sharing information was hard to understand.

Table 25: Parental Assessment of Their Child's Insurance, by Insurance Group			
	Medicaid (N=803-806)* %	NCHC (N=994-1,005)* %	SEHP (N=717-865)* %
Written information about child's insurance plan has been easy to understand [†]	92	97	81
Parent would recommend their child's health insurance to others with a child with special needs [†]	98	99	70
Overall satisfaction with child's health insurance: [†]			
Very satisfied	65	80	22
Somewhat satisfied	29	19	51
Somewhat dissatisfied	4	1	20
Very dissatisfied	2	1	7
*Number of parents responding (N) varies by question.			
[†] Differences across insurance groups are statistically significant at $p \leq 0.01$.			

Parents of children on each of the public insurance programs would recommend the insurance to others with children with special needs. Parents with children on SEHP had more reservations. Parents of children on NCHC were most likely to report being very satisfied with their child's insurance, and parents on SEHP were more likely to report being somewhat or very dissatisfied.

What Parents Like and Dislike about Their Child's Insurance

Parents were asked two open-ended questions that allowed them to express their feelings about their child's health plan, i.e., what they liked best and liked least about the insurance. Responses of the Medicaid and NC Health Choice insurance groups only are reported here because responses of SEHP parents related to specific plan structure issues that are unique to that particular plan and do not provide a useful comparison. A summary of the comments of the parents of children enrolled in the SEHP has been provided to administrators of that plan.

In general, survey respondents are more likely to skip questions that require a written response rather than simply circling or checking a response. In this survey, however, the overall response to these open-ended questions was excellent. Among the parents of children enrolled in Medicaid, 89% (n=738) reported something they liked best about Medicaid and 56% (n=460) reported something they liked least. Response rates for NC Health Choice parents were similar regarding what they liked best (89% or 906 respondents), but only 42% reported something they liked least.

What Parents Like Best

We categorized the written responses to the “like best” question into eight broad descriptive categories (Table 26). Frequently a parent’s written response fell into more than one category. There were differences across the two health plans in the distribution of summarized responses. For parents of children in both plans their most common “like best” was that the insurance enabled them to get health care for their children, including the extent of the coverage and benefits. Parents of NCHC children were more likely to cite other aspects of the program, such the cost sharing being affordable (not relevant for Medicaid), being pleased with program administration, and liking that providers accept the insurance.

Table 26: What Parents Like about Their Child’s Insurance		
	Medicaid (N=825) %	NCHC (N=1,015) %
Reported something they liked best	89	89
<i>What parents like best as a % of ALL survey respondents</i>		
General satisfaction (without detail)	10	14
Access to health care for their child	63	36
Coverage and benefits	27	18
Can choose provider	2	8
Providers accept insurance	2	10
Plan administration	6	13
Cost sharing is affordable	NA	16
No stigma associated with insurance	<1	1

For each category, we include a series of phrases that capture the essence of what people were expressing, but are not the actual words of any one individual in order to ensure confidentiality of individual respondents (Table 27).

Table 27: Sample Positive Comments from Parents about Their Child’s Insurance		
Medicaid – 10%	General Satisfaction	NCHC - 14%
I have never had a problem It’s a blessing I like everything about it I helps you when you are having a hard time I’m a single parent and I couldn’t do without it It’s good when you have a limited income and a child with lots of medical bills Children get care when their families can’t afford it	Less stress now that he can see a doctor as needed Peace of mind My child is healthy, NCHC made that possible I like everything, Thanks for helping single parents This program really helps low income families Someone cares enough to help working people take care of their children	
Medicaid – 63%	Access to Health Care	NCHC - 36%
It pays for care I wouldn’t be able to afford With Medicaid my child does not have to stay home and suffer just because we don’t have money I don’t have to choose between health care and food My child gets the medical care and medicines that he needs I can take care of all his health problems as he is growing up so he will be a successful adult Without it I could not afford the care for my child I’m lucky to have Medicaid because I can’t afford insurance There’s no co-pay or deductible	It’s such a relief that my child can get needed care If my child didn’t have NCHC they would not be able to get care because I can’t afford it I couldn’t get my child the care he needs, now I can Quality care would be financially out of reach without NCHC but now my child gets it It’s been a blessing to know he will get the treatment he needs Our state sees the importance of insuring kids so they can be healthy Without it my child would not have insurance, since most companies won’t insure children with special needs	

Table 27: Sample Positive Comments from Parents about Their Child's Insurance - Continued		
Medicaid – 27%	Coverage and Benefits	NCHC - 18%
It covers everything my child needs Covers hospital and therapies Wide range of services covered It pays for all the medicine she needs I don't have to pay anything out of pocket for medicines Especially that it covers medicine since it is so expensive My child gets needed mental health services Medicaid has covered every needed specialist It's great insurance for a child that needs a lot of therapies	It covers all my child's needs, better benefits than other insurance Most everything he needs is covered 100% Complete range of services Low copay on medicines, Prescriptions are free I don't know what I'd do without NCHC since my child's medicines are very expensive Pays 100% of diabetic supplies My child finally went to the dentist It covers speech rehab It helps us get glasses It covers mental health It covers allergy shots	
Medicaid – 2%	Choice of Provider	NCHC - 8%
I can choose my child's doctors I can take my child anywhere	I can choose who to take my child to I didn't have to switch doctors Don't need a referral to visit a specialist You don't have to get permission to go to a doctor My child can go to a private doctor It's easy to get a doctor close to home	
Medicaid – 2%	Providers Accept the Insurance	NCHC - 10%
Some private providers accept it It's taken almost everywhere Now most places take it No problems taking my child to the dentist My child can get care from almost any doctor	Most places accept it Variety of places that accept it, everybody does No questions asked when you show your card Now I can take him to a dentist close to home I can finally get a dentist, none took Medicaid Doctors who won't take Medicaid will take NCHC With the card doctors don't give you a difficult time	
Medicaid – 6%	Plan Administration	NCHC - 13%
It's easier than other insurance It's easy and no hassle Very convenient - everyone understands exactly what it covers I don't have to file insurance No paperwork to fill out when he goes to the doctor No hassle with paperwork	Claims are paid fast They always let you know when things change The EOB lets you know things were paid People on the phone are polite Everyone is so nice and quick to give you answers The doctors file for you It's a lot easier than Medicaid I don't have to do a bunch of paperwork A card that doesn't change every month You only give your check stubs once a year You don't have to show a card every time you see the doctor It's like BC/BS	
	Cost Sharing is Affordable	NCHC - 16%
	The co-payment is affordable Low co-pay for prescriptions Only \$50 to sign up That there's no copay since if there were a fee I couldn't afford it and my child wouldn't get care	
	No Stigma	NCHC - 1%
	It's non-judgmental Get more respect from providers than when we had Medicaid You're not looked down on My child is treated like everyone else	

What Parents Dislike about Their Child's Insurance

We categorized the written responses to the “like least” question into seven broad descriptive categories (Table 28). For one of these, i.e., problems finding a provider that will accept the insurance, we created a sub-category for people who specifically mentioned finding a dentist as a problem. Again, an individual's response could fall into multiple categories.

There were differences across the two health plans in the types of “like least” responses. The most commonly expressed dislike for the parents of Medicaid children was that providers would not accept the insurance. Although this was also a concern for parents of children enrolled in NC Health Choice, the larger complaint for them was the benefit structure of the plan.

Table 28: What Parents Dislike about Their Child’s Insurance		
	Medicaid (N=825) %	NCHC (N=1,015) %
Reported what they liked least	56	42
<i>What parents like least as a % of ALL survey respondents</i>		
Benefit structure	12	18
Providers will not accept insurance	16	10
(Dentists will not accept insurance)	(8)	(5)
Plan administration	9	6
Need for referrals	11	<1
Eligibility requirements	4	6
Stigma associated with insurance	4	<1
Cost	<1	2

For each category, we include a series of phrases that capture the essence of what people were expressing, but are not the actual words of any one individual in order to ensure confidentiality of individual respondents (Table 29).

Table 29: Sample Negative Comments from Parents about Their Child’s Insurance		
Medicaid – 12%	Benefit Structure	NCHC – 18%
Vision coverage is not enough Can’t get diabetic food Can’t get updated equipment Limits on therapy visits Can’t get asthma equipment and supplies Doesn’t cover all necessary services Not enough allowed prescriptions for children with special needs Doesn’t cover all medicines Can only get generic drugs	Don’t think plan covers psychologist, at least I can’t find one My child really needs braces, they are not covered Doesn’t cover everything, Have to wait too long to get a new pair of glasses Needs better dental Some of her diabetic supplies are not covered Need programs for obese children Her braces were covered on Medicaid Limits on physicals and mental health Copays on prescriptions That name brands are not covered Having to pay for supplies myself and be reimbursed	
Medicaid – 16%	Provider Acceptance	NCHC – 10%
Hard to find places that accept it Some providers who take Medicaid don’t take new patients It’s hard to find a specialist that will take it Hard to find doctor where you aren’t on a waiting list I want a private doctor not a clinic Some doctors don’t take it - it’s hard to get emergency care without going to the hospital The closest dentist that takes it is 50 miles away Only a limited number of dentists accept Medicaid	Some places won’t take it Some facilities are not familiar with it, Severe lack of eye doctors that will take NCHC Most doctors won’t see my child - they say they don’t get paid The good doctors don’t accept it It doesn’t seem as easy to get care as it was with Medicaid No dentist accepts NCHC but the health department No dentist near my home will take it, none	

Table 29: Sample Negative Comments from Parents about Their Child's Insurance - Continued		
Medicaid – 12%	Plan Administration	NCHC – 18%
Caseworker keeps changing so you never know who to talk to The monthly paper work and card People aren't always nice Hard to reach case workers by phone and they don't return calls Sometimes the card doesn't come on time and the doctor won't see you and you can't get a prescription filled The size of the card Pharmacies don't always know about program changes Need materials in Spanish	That you have to reapply every year Social services loses my paperwork The paperwork Need list of who participates especially dentists Too much time to get approval for special services Not enough info on how long you can buy it if you no longer qualify I can't get my questions answered Customer service people are not always kind Need a second card Customer service takes a long time Billing confusion	
Medicaid – 11%	Need for Referrals	NCHC – <1%
Can only go to one doctor and sometimes you can't get in Having to go through your doctor to go to the ER Hard to take your child somewhere else when your doctor's office is closed My child got a lot worse waiting for a referral to a specialist	Too much red tape to see a specialist You need pre-approval for speech therapy	
Medicaid – 4%	Eligibility	NCHC – 6%
Income level is too low I worry my child will lose eligibility and have no coverage Older children lose coverage If your income goes over the limit by even \$1 you have to switch to NCHC and switch doctors I'm afraid my child will lose coverage if I get a job	That it's only for children I worry my child will lose this insurance if my income goes up just a little The income limits are too low I wish you could buy it for more than one year That state funds could run out One of my kids is not on NCHC because of closed enrollment ²	
Medicaid – 4%	Stigma Associated with Insurance	NCHC – <1%
You get poor service You're treated differently You have to wait a long time They take their time getting to you when you are on Medicaid Your children are treated as if they're less important	You're treated differently People think it's Medicaid and treat you like you're useless	
	Cost Issues	NCHC – 2%
	Hard to pay Sometimes I get bills	

SUMMARY AND DISCUSSION

This report presents results of a survey of parents of children with special health care needs as identified by diagnosis codes from health care claims data. Although this method for identifying a sample is not ideal, only a small percentage of parents did not report either a health problem or service use that is consistent with a broad list of problems that could indicate a need for ongoing and/or comprehensive health care. To the extent that our sample includes children without special health care needs, and therefore children who would not have tried to access services addressing special needs, our estimates of the access problems faced by children with special health care needs in North Carolina are conservative.

Access to Medical Care

Reported access to medical care, both general and specialty care, was relatively good for children in all three insurance programs. Few children had no general provider. About half received care from a medical specialist. Children in the SEHP insurance group were more likely to have a medical specialist, despite the fact that this group was reported by parents to be the healthiest of the three on several measures. The reasons for the inverse relationship between

² At the time of the survey, enrollment of new children in NCHC was frozen due to limitations of funding.

children's health and use of specialty care are unclear. Greater use of specialty care by SEHP children may be due less to greater need for such care than it is to parental ability to self refer and advocate for their child, higher income, or flexibility in the parent's work schedule. On the other hand, if SEHP children have had better access to specialty care throughout their lives, their parents might perceive them to be in better health as, indeed, they might be.

Unmet need for both general medical care and specialty care was relatively low overall, but the 10% of Medicaid parents who reported unmet need for both types of care was double that of children in each of the other two insurance groups. Levels of unmet need for NCHC children were comparable to those for children in the SEHP. Some differences in access between Medicaid and the other two insurance groups are, no doubt, related to better acceptance of NCHC and SEHP by providers due in part to higher reimbursement levels. Other reported barriers to care for those on public insurance related more to the challenges of daily life faced by the economically disadvantaged. Parents of Medicaid and NCHC children reported problems with transportation and problems seeing a doctor due to inconvenient office hours. Although some parents of Medicaid children with access problems did report that they could not find a provider that would see their child for general medical care, difficulty finding a provider appeared to be less of an issue than logistical problems.

There were also differences in the site of general medical care with publicly insured children more likely to be seen in public facilities or hospital clinics and less likely to be seen in private offices. Although children in both public programs were more likely to be seen in the public sector than were SEHP children, Medicaid children were even less likely than NCHC children to receive care in the private sector. Lower Medicaid provider reimbursement levels probably drive some of the observed differences in site of care, but that cannot be the only explanation since NCHC children are less likely to see private providers than are SEHP children even though reimbursement levels for these two insurance plans are the same. Consistent with differences in site of medical care, Medicaid children were most likely to receive special services at school or day care for their health or developmental condition, followed by NCHC children and children on SEHP.

Children in the Medicaid group used the ER more frequently than did children in the other two insurance groups, with use being the lowest among children enrolled in SEHP. Only two-thirds of ER visits were made because the parent believed their child's condition to be an emergency or because they had been advised by a health care professional to seek care in the ER. One-third of parents sought ER care for other presumably non-emergent problems. Of importance to this study is that there were no differences in the percentage of ER visits that were considered to be emergent across insurance plans. Among the diagnosis groups, asthma was associated with higher ER use, and among children with asthma, Medicaid children were more likely to go to the ER than were children in the other two insurance groups. Although our measure of the appropriateness of ER care is imprecise and not validated by medical records, it is likely that a large portion of visits we classified as non-emergent were just that. Use of the ER for primary care is a longstanding problem. For parents who report transportation problems and difficulty getting convenient appointments, use of the ER in the evening may be their only option for care. It is more difficult to make that argument for many parents on SEHP although there is a range of income for state employees and there are likely some SEHP parents who face similar barriers. Another consideration is the clarity of instructions by and access to primary care providers after office hours. Parents who experience difficulty communicating with their child's

primary care provider may use the ER as an alternative source of care. This could account for some of the use of the ER for nonemergent care regardless of insurance.

Prescription Drugs, Medical Equipment and Supplies

Almost all of the children in our survey had received a prescription sometime in the previous six months and there were few reported barriers to receipt of prescription medication for any group of children. There were, however, significant differences in parents' ability to get needed medical equipment and supplies, with parents of children in NCHC reporting the most difficulty. One-quarter of NCHC parents reported unmet need for medical equipment or supplies, a concern given that most equipment and supplies that could not be obtained are covered under the plan. Based on anecdotal reports by parents in other parts of the survey it appears that access problems could be due to a number of factors. First, at the time this study was conducted pre-approval was required for items costing more than \$250. Parents reported that the prior approval process was slow and sometimes frustrating. It is important to note that NCHC benefits have changed and prior approval is now only required when the cost of equipment is greater than \$1,000. Second, a number of parents believed that the items were not covered. Finally, it appears that some vendors required parents to pay for the equipment or supplies out-of-pocket and be reimbursed. Some parents had difficulty finding the funds for this initial cash outlay.

Access to Special Therapies, Home Health and Respite Care

For all of the specialized therapies queried (respiratory, speech and physical/occupational therapy), parents of Medicaid children were significantly more likely to report that their child needed these services. This finding is consistent with the fact that Medicaid children were also reported to be in less good health than children in the other two insurance groups. Although the need was greatest among Medicaid children, SEHP children had more difficulty accessing therapy services, particularly speech therapy. Very few parents reported the need for either home health or respite care, but among parents with such need, unmet need was high, particularly for respite care, where over half of the parents in each insurance group who reported the need for such care were unable to get it.

Access to ADD/ADHD and Mental Health Services

Children on Medicaid were significantly more likely to have problems accessing ADD/ADHD or mental health/substance abuse services, with rates of unmet need that were twice as high as those for NCHC children for both types of services and three times that of SEHP children for ADD/ADHD services. For both of these types of services, children on Medicaid were more likely to receive care in the public sector than were children in either of the other insurance groups.

There are not clear patterns of barriers to receipt of ADD/ADHD or MH/SA care. Many parents identified insurance barriers including the insurance not paying for care and limits to the number of visits allowed. Provider barriers were reported for all insurance groups, including the inability of parents to find a place to take their child or inconvenient office hours of available providers. A large number of responses listed under "other" by parents also addressed parental difficulties with providers such as dissatisfaction with care or lack of appointments. As was seen

throughout the survey, barriers associated with poverty including transportation issues and inconvenient office hours were again problems. For mental health services, refusal of the child, likely an adolescent, to go for care was reported by parents in all groups.

Access to Dental Care

Parents of children covered by SEHP reported better access to dental care than did parents of children on Medicaid and NCHC despite the fact that the SEHP does not cover dental care and many children in SEHP probably do not have dental insurance. Medicaid children faced the greatest barriers, with almost one-quarter of Medicaid parents reporting that their child needed dental care but could not get it, compared to 18% of NCHC parents. As was reported for medical care, Medicaid children were more likely to receive dental care in the public sector or from multiple providers than were NCHC children.

For dental care, it is possible that lower provider reimbursement levels are a significant factor in the limited access of Medicaid children to these services. Almost two-thirds of the Medicaid parents who reported an unmet dental need said that they could not find a provider who would accept the insurance. Fewer NCHC parents (46% of those whose child had an unmet dental need) reported that the inability to find a dental provider who would take NCHC was a barrier, but it was still the most common barrier reported by this group. Barriers to dental care reported by SEHP parents pertained primarily to payment issues, but we do not have information on supplemental dental insurance for this group to determine to what extent barriers were related to insurance limits versus the ability of SEHP parents to afford the out-of-pocket costs for dental care.

Case Management

Just over one in ten children in the sample had a case manager/care coordinator, with more children on Medicaid receiving such services. Although some of this difference is explained by the fact that some case management programs are available only for the young children and the Medicaid sample has more children five years of age and under, differences among insurance groups remain when considering only the older children. Among children without case managers, most parents reported that they had never heard of such services or that their child did not need these services. Although efforts were made to clearly define the type of services being queried in this series of questions, the term “case management” can mean different things to different people and for some has no meaning at all.

STUDY LIMITATIONS

This study was designed to compare parentally reported access to care for children with special health care needs insured by three different insurance plans. Identifying an appropriate sample of CSHCN is difficult even within a single insurance plan, and is even more problematic when including children from multiple plans. Care seeking behavior will vary with the structure of the insurance plan and characteristics of plan enrollees. This study used health care claims diagnoses to identify children for the study. As was discussed above, there are three limitations to interpretation of the study results. First, use of health care claims precludes selection of children who get no care at all, a group for which a study of access is particularly important. We do not believe this is a major problem for this study as most conditions selected for inclusion in

the sample frame would necessitate some type of health care even if only in the emergency room. Second, health care claims diagnoses may not accurately reflect the extent of the health problem or even the existence of the problem. In this study, more than three-quarters of parents reported that their child had an on-going health problem. To the extent that children of those who reported no problems actually had no problems, these results underestimate need for and access to care by children with special health care needs in the different insurance plans. Finally, lack of information for one insurance group precluded weighting the study results to represent the larger universe of insured children with special health care needs from which the sample was drawn.

CONCLUSION AND RECOMMENDATIONS

We find that differences across insurance plans are consistent throughout the survey results and support a gradient of need and access to care that ranges from more need and less access for Medicaid children to less need and more access for SEHP children, with NCHC children falling in the middle. The strength of this finding is supported by the fact that parental report of their child's health status is consistent with reported use of health care and ancillary services and barriers to these services. What cannot be determined by this study is the extent of the association between good health and health insurance. Confounding the interpretation of these results is the socioeconomic gradient across the three insurance groups and the extent to which socioeconomic advantage contributes to good health in multiple facets of daily life. In addition, economically stressed parents may report less unmet need because of lowered expectations of the health care system and health insurance system, a factor that we were unable to measure in this study. Parents may report that their child received all the services s/he needed because the parent did not know what more could be done or did not expect to receive more.

The encouraging news is that, with the exception of dental care, there do not appear to be major areas of unmet need. However, even though the percent of parents of children on Medicaid or NCHC who reported unmet need was relatively small, if these percentages are applied to large numbers of enrollees the absolute number of children with unmet need is large.

While most children have access to providers for care, children on Medicaid in particular, and to a lesser extent those on NCHC, were reported to be less likely to receive care in the private sector. This finding is problematic to the extent that some public providers do not offer comprehensive services. Also, the greater use of public providers by Medicaid children compared to NCHC children suggests that, should NCHC reimbursements levels decrease to Medicaid levels, there would be a movement of NCHC children away from the private sector, and the need to maintain a strong public safety net would increase.

The study findings suggest that ER use for non-emergent problems remains a concern. Parental report of the reasons for such use indicate the need for more extensive primary care coverage, parental education, and family-friendly office policies such as evening and weekend hours.

The findings of poor access to dental care for CSHCN, especially Medicaid enrollees, are consistent with other studies of access to dental care for all low-income children in North Carolina. The fact that SEHP children, many of whom may have no dental insurance at all, had better access to services underscores the problem North Carolina faces in insuring an adequate

supply of dentists that are willing to serve low-income children. Although the improvement in access seen for NCHC children compared to Medicaid children suggests that increased provider reimbursement might improve access for children on Medicaid, the access levels of NCHC children are still not adequate. Also, anecdotal reports suggest that there are a limited number of “slots” for dental care for low-income children either because dentists will not see any publicly insured children or limit the number of these patients they will accept. It is not clear how much dentists limit the number of publicly insured patients they will see because of reimbursement rates or for other reasons. To the extent that these limits are based on multiple factors, an increase in reimbursement rates alone will not ensure access. Other methods need to be found that will encourage dentists to serve low-income children and support families to enable them to keep appointments.

While the majority of CSHCN do not appear to need medical equipment and supplies, for those who do, the inability of many NCHC children to obtain these items is worrisome. The program has already addressed some of the barriers reported by parents. With the increase from \$250 to \$1,000 in the allowable cost for purchasing equipment without prior approval, some equipment reported by respondents as unavailable (such as nebulizers) would now be available. There were also reports of barriers imposed by some vendors who required that parents pay out-of-pocket for some supplies. This access problem could be addressed by changing the relationship between vendors and the insurance plan, possibly requiring that vendors not charge the parent and ensuring that reimbursement to vendors is timely. Finally, some parents commented on the limited number of supplies such as test strips that they could get for their child each month. These comments are puzzling since there are no such limits under either Medicaid or NCHC. It is possible that the monthly limit comes from the number of supplies indicated on the prescription written by the physician. If true, this is not a problem that can be addressed by changes to the insurance, but rather requires educating parents regarding the need to contact their physician for a new, larger prescription.

In general, it appears that poverty creates access problems independent of insurance coverage as evidenced by reports of transportation barriers and barriers due to inconvenient office hours that reflect in part difficult and inflexible work schedules for the poor. Although Medicaid children are technically eligible for transportation services, it appears that not all families’ needs are being met, possibly due to the differing methods of covering transportation needs and the level of responsiveness to acute transportation needs in individual counties.

Our ability to draw detailed conclusions about any one diagnosis group was limited by the necessity to include multiple diagnosis groups in our sample and the resultant small numbers of respondents representing any one diagnosis group. The study findings do suggest areas of concern that would benefit from more in depth study. Detailed studies of diagnosis groups that are prevalent or increasingly prevalent, such as asthma, diabetes, and ADD/ADHD, or studies of specific services such as mental health services or dental care where concerns about provider supply exist, would allow a more precise comparison of the influence of insurance on access to care. In addition, the identification of children in specific programs such as case management, and comparison of these children to children with similar health care needs but without these services could elucidate the strengths and shortcomings of these programs.

In summary, parents in all insurance programs report that health insurance is an essential component in their efforts to keep their children healthy. The North Carolina Health Choice

program appears to provide better access to services for children with special health care needs than does the Medicaid program but it is not possible to separate out the relative effects on access to care that come from the general willingness of providers to serve low-income children, the influence of provider reimbursement rates that affect provider willingness, and the effects of poverty on the daily life of families.